

## Aggressiveness of Cancer Care Near the End of Life: Is It a Quality-of-Care Issue?

Craig C. Earle, Mary Beth Landrum, Jeffrey M. Souza, Bridget A. Neville, Jane C. Weeks, and John Z. Ayanian

From the Division of Population Sciences, Department of Medical Oncology, Dana-Farber Cancer Institute; Department of Health Care Policy, Harvard Medical School; and the Division of General Medicine, Brigham and Women's Hospital, Boston, MA.

Submitted December 14, 2007; accepted May 20, 2008.

Supported by Grant No. CA 91753-02 from the National Cancer Institute.

Presented in part at 42nd Annual Meeting of the American Society of Clinical Oncology, June 2-6, 2006, Atlanta, GA.

Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

Corresponding author: Craig C. Earle, MD, MSc, Institute for Clinical Evaluative Sciences, Sunnybrook Health Sciences Centre, 2075 Bayview Avenue, Room G-106, Toronto, Ontario, M4N 3M5 Canada; e-mail: craig.earle@ices.on.ca.

© 2008 by American Society of Clinical Oncology

0732-183X/08/2623-3860/\$20.00

DOI: 10.1200/JCO.2007.15.8253

### ABSTRACT

The purpose of this article is to review the literature and update analyses pertaining to the aggressiveness of cancer care near the end of life. Specifically, we will discuss trends and factors responsible for chemotherapy overuse very near death and underutilization of hospice services. Whether the concept of overly aggressive treatment represents a quality-of-care issue that is acceptable to all involved stakeholders is an open question.

*J Clin Oncol* 26:3860-3866. © 2008 by American Society of Clinical Oncology

### INTRODUCTION

Despite advances in the early detection and treatment of cancer, a large proportion of patients still eventually die as a result of their disease.<sup>1</sup> Many of the issues these people face near the end of life are similar, regardless of their initial type of cancer. Therefore, the quality of medical care delivered to cancer patients near the end of life is of significant concern. Despite this, there has been relatively little work done to find ways to evaluate the quality of care that patients with incurable cancer receive.

The National Cancer Policy Board has defined poor-quality care as when "practices of known effectiveness are being underutilized, practices of known ineffectiveness are being overutilized, and when services of equivocal effectiveness are being utilized in accordance with provider rather than patient preferences."<sup>2</sup> In an effort to address the gap in quality measurement for cancer patients near the end of life, we have previously used systematic literature review, focus groups with terminally ill cancer patients and bereaved family members, and an expert panel of physicians using a modified Delphi approach to identify and operationalize potential quality measures that could be evaluated with existing administrative data.<sup>3</sup> These exercises identified an overarching theme of overly aggressive cancer treatment as potentially representing poor-quality care, and produced a set of measures assessing three major areas: (1) the overuse of chemotherapy very near death; (2) possible misuse of treatment resulting in high rates of emergency room visits, hospitalization, or intensive care unit stays for terminal patients; and (3) underuse of hospice services as measured both by lack of referral or very late referral to hospice. We have applied these measures to co-

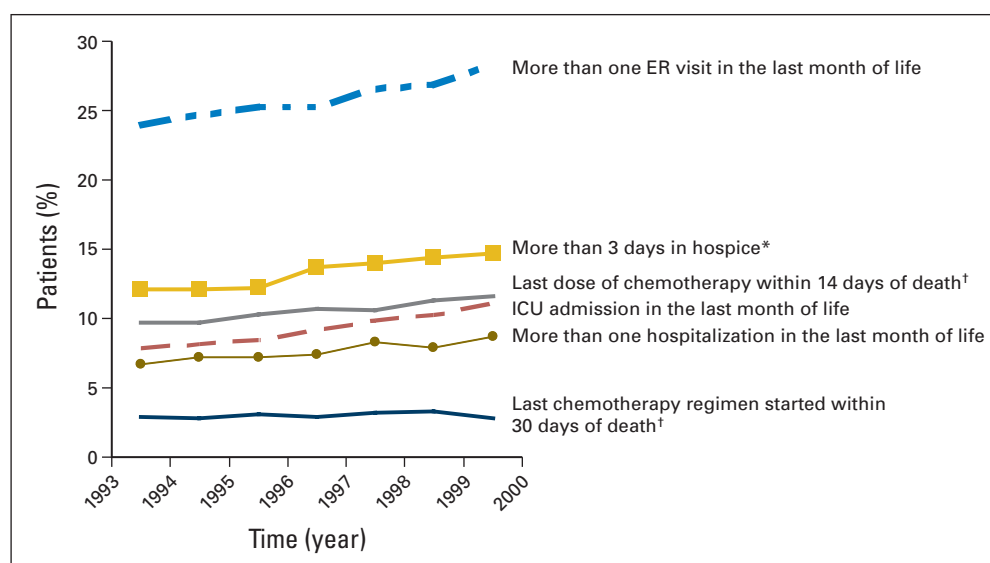
horts of patients with common aggressive solid tumors to define benchmarks empirically, evaluate the accuracy of the claims, assess reliability of the measures, and investigate geographic variation in practice.<sup>4</sup> From these analyses, we have previously reported secular trends of increasingly aggressive cancer care near the end of life during the mid-1990s.<sup>5</sup> In this article, we will review the literature on the aggressiveness of cancer treatment near the end of life and update analyses of practice patterns and methodologic development, focusing on the more methodologically sound measures of chemotherapy and hospice utilization near death.

### TRENDS AND PREDICTORS OF AGGRESSIVE CANCER CARE

Figure 1 and Table 1 show updated data on the trends and predictors of aggressive care near the end of life. This cohort consists of all 215,484 patients who died as a result of any malignancy, of any duration, between 1991 and 2000, who had been diagnosed while living in an area monitored by one of the Surveillance, Epidemiology, and End Results (SEER) registries, who were age 65 years and older at death, and enrolled in both parts of Medicare in the 3 months before death. We examined their Medicare claims to determine practice patterns following methods we have previously reported (Appendix Table A1, online only),<sup>4,5</sup> and supplemented sociodemographic information with geographic characteristics linked from the National Center for Health Workforce Information and Analysis' Area Resource File and physician information from linking the American Medical Association Master File.

Figure 1 depicts trends over time in the aggressiveness of cancer care near the end of life. As we

# Consistency of End-of-Life Measures



**Fig 1.** Updated trends in the aggressiveness of cancer care near the end of life, all cancer types, all durations of disease among 215,484 Medicare enrollees in Surveillance, Epidemiology, and End Results (SEER) areas who died as a result of cancer. (\*) Among patients admitted to hospice. (†) Among patients who received chemotherapy. ER, emergency room; ICU, intensive care unit.

found in our previous analyses, most measures show an intensity of care that is continuing to increase. The proportion of patients still receiving chemotherapy within 14 days of death continues to rise monotonically, up from 9.7% in 1993 to 11.6% by 1999, although we could not detect an increase in proportion starting a new regimen

within the last month of life in this analysis. Although overall hospice utilization is increasing (Table 1), a large proportion of this increase represents patients admitted within 3 days of death, which accounted for 14.3% of all hospice admissions in 1999. We have also looked at several of these measures using the MarketScan MEDSTAT database

**Table 1.** Logistic Regression Analyses Predicting Aggressive Care

Factor	Chemotherapy Within 14 Days of Death		Lack of Hospice		Hospice Admission ≤ 3 Days Before Death*	
	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI
<b>Patient characteristic</b>						
Year of death	1.06	1.06 to 1.07	0.85	0.85 to 0.86	1.03	1.03 to 1.04
Age at death	0.94	0.94 to 0.94	1.01	1.00 to 1.01	0.99	0.99 to 0.99
Male	1.07	1.02 to 1.12	1.23	1.20 to 1.25	1.27	1.21 to 1.33
Black race	0.74	0.67 to 0.81	1.17	1.13 to 1.21	0.81	0.75 to 0.88
Other race	0.84	0.75 to 0.93	1.52	1.45 to 1.59	NS	
Single/widowed v married	0.77	0.74 to 0.81	1.16	1.14 to 1.19	0.95	0.91 to 0.99
Charlson score	0.92	0.90 to 0.95	1.09	1.07 to 1.10	1.05	1.02 to 1.07
SES decile	1.03	1.02 to 1.04	0.98	0.98 to 0.98	NS	
<b>Cancer characteristics</b>						
Disease site						
Colorectal	1.20	1.12 to 1.30	0.94	0.91 to 0.97	NS	
Breast	1.63	1.49 to 1.78	1.21	1.16 to 1.26	1.21	1.11 to 1.33
Lung	NS		NS		NS	
Prostate	NS		0.95	0.92 to 0.99	0.89	0.81 to 0.96
Hematologic	2.10	1.96 to 2.24	2.06	1.99 to 2.14	1.64	1.52 to 1.77
Nonmetastatic initial stage	0.82	0.79 to 0.86	1.06	1.04 to 1.08	0.89	0.86 to 0.94
Survival time (years)	0.98	0.97 to 0.99	0.99	0.98 to 0.99	0.98	0.97 to 0.99
<b>Provider characteristics</b>						
Teaching hospital	1.17	1.12 to 1.23	0.94	0.93 to 0.96	1.15	1.10 to 1.20
Oncologist	1.49	1.31 to 1.70	0.54	0.50 to 0.57	1.26	1.13 to 1.42
PCP	0.78	0.72 to 0.84	0.68	0.67 to 0.70	1.35	1.27 to 1.42
<b>Area characteristics</b>						
Availability of teaching hospitals	1.07	1.04 to 1.10	0.88	0.87 to 0.89	1.14	1.11 to 1.17
Hospice availability	0.94	0.92 to 0.97	0.97	0.96 to 0.98	0.84	0.82 to 0.86

NOTE. Among 215,484 Medicare enrollees in Surveillance, Epidemiology, and End Results areas who died as a result of cancer. Main effects only. Abbreviations: SES, each decile of increasing socioeconomic status; oncologist, ever saw oncologist in last month of life; PCP, ever saw a primary care physician in the last month of life.

\*Among patients who received hospice care (n = 82,579).

to evaluate a cohort of 18,812 younger, commercially-insured patients dying of cancer between 1991 and 2003. This analysis produced similar findings. Among those receiving chemotherapy in this MEDSTAT database, 17.1% were still being treated within 2 weeks of death and 9.7% had more than one hospitalization in the last month of life. Only 23.3% received any hospice care.

Table 1 shows logistic regression analyses predicting chemotherapy use within 14 days of death, hospice referral, and, among those referred to hospice, predictors of the likelihood that they would be admitted within 3 days of death. Measures focusing on emergency room visits, hospital admissions, and intensive care unit utilization were not included because we have found them to be strongly influenced by comorbidity and, therefore, appear less useful as measures of aggressive cancer care. This analysis confirms the secular trend that each successive year of death is independently associated with an increasing likelihood of patients experiencing late chemotherapy use and short hospice admissions. As with our previous findings, elderly, female, nonwhite, and unmarried patients were less likely to receive aggressive care. Not surprisingly, the hematologic malignancies were most strongly associated with aggressive care. Those who presented initially with early-stage cancer and later relapsed, and those with a longer duration of illness were less likely to be treated aggressively near the end of life. Patients cared for by an oncologist in the last month of life were more likely than those cared for by other types of physicians to be treated late with chemotherapy, and to be admitted to hospice; however, they were also more likely to initiate hospice within 3 days of death. Others have similarly found that patients cared for by oncologists were referred to hospice later than those cared for by other physicians.<sup>6</sup> As we found before, both receiving care in a teaching hospital and simply living in an area with more teaching hospitals appears to predispose to more aggressive care, while the local availability of hospice services leads to greater hospice utilization and a decrease in aggressive chemotherapy use. Teaching hospitals are associated with greater overall use of hospice, however.

#### **"CONTINUATION OF CHEMOTHERAPY VERY NEAR DEATH MAY INDICATE OVERUSE"**

Because of their rigorous methodologic development, the measures of cancer care intensity described above have been endorsed by the National Quality Forum (NQF) as surveillance measures for end-of-life care, and were recommended for further development to be used for quality-improvement purposes. The Agency for Healthcare Research and Quality (AHRQ) is currently funding contracts to validate these specific measures further. They have also undergone testing in other health care settings and in other countries.<sup>7,8</sup> One reason for this interest is that they have the relatively unique feature of assessing overuse. Oncologists have traditionally focused on underuse (surgery, adjuvant chemotherapy or radiation) as the source of most quality problems, with little attention to the possibility that overuse could result in poor quality care.

There is evidence that the use of chemotherapy near the end of life is not related to its likelihood of providing benefit.<sup>9</sup> Indeed, we found in our analyses that the mean duration of the last treatment regimen, which is sometimes used as a proxy for time to progression, was stable at 61 days during the last decade, whereas overall chemotherapy utilization was increasing. This suggests that there was no

increase in effectiveness of the chemotherapy being used, with patients mostly coming off treatment when restaged after approximately 2 months. So, why does overly aggressive care occur? In a survey of Medicare beneficiaries, observed geographic variation in end-of-life treatment could not be explained by patient preference,<sup>10</sup> suggesting that physician practice style is a major driver.<sup>11</sup> There are many rationales for recommending treatment with very limited potential benefits. For example, it can be seen as providing hope. Moreover, the discussion about changing the focus of treatment from fighting the cancer to providing symptomatic and supportive care is a difficult one that nobody relishes.<sup>12</sup> It is often easier to recommend another line of chemotherapy. The issue can be complicated by oncologists' anecdotal experiences of occasional patients who seemed to actually respond to late-line treatment, a concern that is becoming even more relevant now that relatively nontoxic targeted agents are altering the risk/benefit calculation. And lastly, there may be financial incentives. Jacobson et al<sup>13</sup> explored whether physicians who were relatively more generously reimbursed for chemotherapy made different decisions in situations with substantial clinical discretion about whether to give treatment and which drugs to use, namely the management of metastatic common solid tumors. They found that reimbursement did not affect the decision to give chemotherapy or not, but once that decision was made, oncologists tended to use drugs for which they were reimbursed the most. For example, a \$33 increase in reimbursement for carboplatin was associated with 17% higher utilization of that drug.

On the other hand, patients may request an aggressive treatment approach right to the end. They may not understand their true prognosis,<sup>14</sup> have unrealistic expectations about the benefits of chemotherapy,<sup>15</sup> want to be "a fighter," or feel that doing something (anything) is better than doing nothing.<sup>16,17</sup> Moreover, it has been shown many times that patients will accept much more toxicity for a smaller benefit than will providers.<sup>18</sup> This observation is commonly put forward to suggest that physicians cannot make these treatment decisions for patients. It begs the question, however, of why oncologists agree to provide treatments to patients that they would not take themselves.<sup>19</sup> By shepherding many patients through the journey towards death, oncologists have a broader perspective and experience than their patients can possibly have. Consequently, oncologists must be prepared to tell patients when they would be better off without the next line of possible chemotherapy.<sup>20</sup>

#### **"A HIGH PROPORTION OF PATIENTS NEVER REFERRED TO HOSPICE, OR REFERRED ONLY IN THE LAST FEW DAYS OF LIFE, MAY INDICATE POOR-QUALITY CARE"**

Hospice availability appears to independently affect physician practice, even the propensity to give chemotherapy. If high-quality palliative care is not available, oncologists apparently tend to continue giving chemotherapy longer than they otherwise would. Uneven access to hospice based on geography, rural settings, and patient socio-demographic factors have all been documented.<sup>21-24</sup> Studies have shown that patients in health maintenance organizations (HMOs) are more likely to receive hospice care, possibly reflecting more coordinated and appropriate treatment patterns.<sup>25</sup> However, it is also argued that this reflects a financial incentive to offload relatively expensive patients from the managed care organization's panel.<sup>22</sup> Even when hospice is available, however, barriers still exist. Some patients may

associate it with a stigma. Some are unable to get supportive medications such as growth factors or narcotic pumps because of policies necessitated by the hospice benefit, which pays hospices in the range of \$100 to \$150 (the exact amount varies by geography) per day to manage the patient's care, including all medications.<sup>26</sup> The increased overall use of hospice with concomitant increase in the proportion admitted within 3 days of death that we have observed raises the question of whether patients are simply being admitted to hospice to manage death, rather than obtaining the benefits of symptom management and palliative support that hospice can provide.<sup>27</sup>

## RECENT METHODOLOGIC DEVELOPMENT

### Stability Over Time

We and others have documented significant variation in practice patterns regarding these measures.<sup>4</sup> For example, the American Society of Clinical Oncology's (ASCO) Quality Oncology Practice Initiative (QOPI) reported at the ASCO Annual Meeting in 2006<sup>28</sup> that among 455 patients in 22 practices, use of chemotherapy within 14 days of death ranged from 0% to 33%. This was strongly correlated with either no hospice admission or admission only within less than a week before death. The proportion of patients enrolled in hospice before death ranged from 25% to 100%, with a mean of 62%. Wennberg et al<sup>29</sup> noted similar large variation in similar measures applied to the care at hospitals listed in the 2001 *US News & World Report* "best hospitals" list.

We further assessed the stability of these measures over time by examining the stability of relative aggressive care over time. If the relative aggressiveness of a provider or organization's practice appeared to change from year to year, then these measures might not be assessing a stable property of practice. To investigate this, we used hierarchical regression models to estimate regional variation in both levels and trends of each measure. We used as our geographic unit of analysis the Health Care Service Area (HCSA). HCSAs are groupings of Metropolitan Statistical Areas defined by the Centers for Medicare & Medicaid Services (CMS) based on observed patient flow patterns in Medicare for tertiary care.<sup>30</sup> As such, each HCSA can be considered to be a self-contained regional health system with a related group of providers. We ranked each region according to the model-estimated rate of each indicator and computed the correlation among relative ranks of each region during the 10-year study period. We observed significant variation both in levels of aggressive care and in trends in aggressiveness over time. As Table 2 indicates, the relative rankings of HCSAs from 1 year to the next were stable, with correlations of ranks ranging from 0.91 to 0.98 from 1991 to 1992, and still good to excellent

correlations of 0.66 to 0.84 over the 5-year span from 1991 to 1995. This stability of regional practice patterns provides supportive evidence of the reliability of these measures. However, we found only moderate correlations ranging from 0.40 to 0.61 during the entire decade, which is to be expected even with reliable measures because of differing strengths of trends in different regions eventually altering the relative rankings over time. For example, the poor correlation of hospice utilization over the 10-year period could reflect differential investment in hospice services in different regions. Figure 2 shows HCSAs in the regions monitored by the SEER program that consistently rank in the top and bottom 25 (of 77 HCSAs) of aggressiveness on each measure. One thing that is apparent is that these measures are evaluating different constructs: Counties that consistently have high rates of chemotherapy utilization within 14 days of death are not necessarily the same ones that have low hospice utilization or a high proportion of hospice admissions within 3 days of death.

## VALIDITY

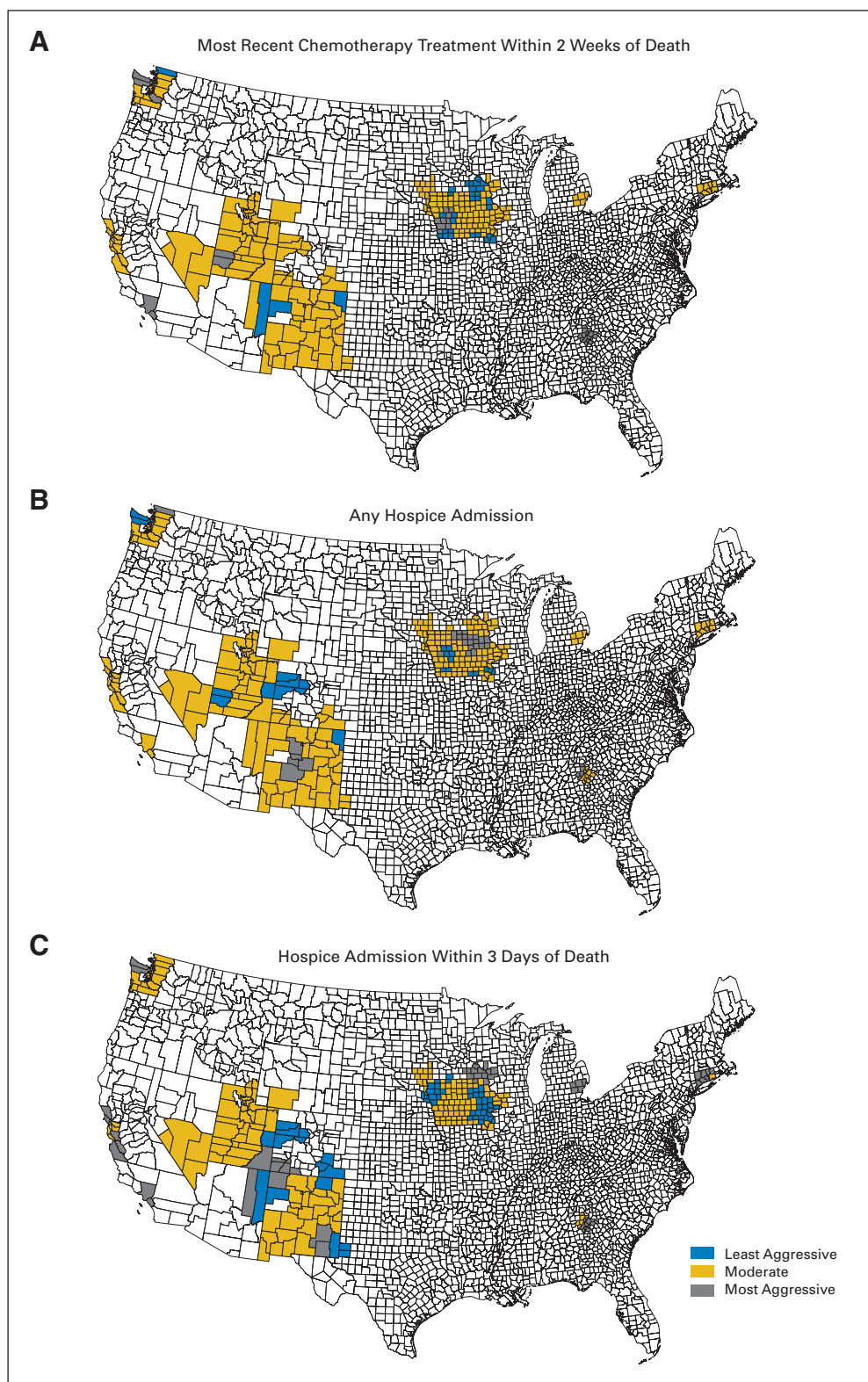
To explore the validity of the measures, we sought to relate each of our measures to the outcome of family members' satisfaction with quality of care near the end of life. We have examined data from a prospective cohort study looking at patient and family needs among women with hormone-refractory metastatic breast cancer treated at two Canadian regional cancer centers, and limited analysis to the patients who died during follow-up.<sup>31</sup> Family members were asked to complete the FAMCARE instrument<sup>32</sup> within 2 weeks of patient death. FAMCARE is a 20-question survey that asks about satisfaction with symptom control, psychosocial care, information provision, and availability of providers. Among 51 consecutive women who died and had a caregiver complete the FAMCARE instrument, there were trends toward less satisfaction with care when chemotherapy was continued within 14 days of death, death occurred in an acute care setting, or there was no or only a short ( $\leq 3$  day) hospice involvement. These did not reach statistical significance, however, perhaps because of the small sample size. Interestingly, variability in scores appeared to be mostly driven by the "information giving" and "physical care" subscales of the FAMCARE instrument, suggesting that inadequate communication and symptom management may be associated with aggressive anticancer treatment. A larger validation study is underway in the National Cancer Institute-funded Cancer Care Outcomes Research and Surveillance (CanCORS) consortium<sup>33</sup> comparing these measures with patient and family assessments of the overall quality of care patients with lung or colorectal cancer receive before death.

**Table 2.** Correlation in HCSA Ranks Over Time Among 215,484 Medicare Enrollees in SEER Areas Who Died As a Result of Cancer

Correlation in Ranks	New Chemotherapy in the Last Month of Life	Chemotherapy Dose During the Last 2 Weeks of Life	> 1 ER visit	> 1 Hospital Admission	ICU Admission	Hospice Admission	Hospice LOS < 3 Days
1991-1992	0.92	0.94	0.91	0.97	0.97	0.98	0.98
1991-1995	0.73	0.66	0.71	0.78	0.84	0.85	0.79
1991-2000	0.54	0.40	0.55	0.47	0.61	0.26	0.44

Abbreviations: HCSA, Health Care Service Area; SEER, Surveillance, Epidemiology, and End Results; ER, emergency room; ICU, intensive care unit; LOS, length of stay.





**Fig 2.** Maps showing distribution of aggressive chemotherapy use and hospice underutilization among 215,484 Medicare enrollees in Surveillance, Epidemiology, and End Results (SEER) Health Care Service Areas (HCSAs) who died as a result of cancer between 1991 and 2000. Gray HCSAs were ranked in the top 25 of 77 HCSAs monitored by SEER every year for 10 years, blue HCSAs were ranked in the bottom 25, and the rest are indicated by yellow. White HCSAs are those not monitored by the SEER program.

## DISCUSSION

Donabedian<sup>34</sup> articulated the rationale for quality measurement as “create an environment of watchful concern that motivates everyone

to perform better.” In this conceptual framework, health care providers are more careful if they know their clinical decisions are being monitored. By monitoring care and providing feedback on performance measures to providers with benchmarking to the performance

of their peers, most providers will examine their own practices for potential areas of improvement. In this way, monitoring performance can improve performance. We have systematically identified a series of candidate performance measures that can be applied to administrative data to profile cancer care near the end of life and have taken an empirical approach to assessing their properties. In the updated analyses presented here, we found predictable patterns over a broader array of clinical situations and consistent rankings of geographic service delivery areas over time. These results support the use of these performance measures for surveillance of end-of-life care.

There are some limitations to these measures, however. They have been mostly developed by assessing the care of elderly patients with fee-for-service insurance, and practice patterns may have been different for younger, commercially-insured patients. Because cancer is commonly a disease of the elderly, though, more than half of all cancer care in the United States is covered by Medicare. The SEER-Medicare database also represents only specific geographic locations and misses the 10% to 15% of patients enrolled in Medicare HMOs. Measures that start with death and look backward are inherently artificial because decisions are made in real time, prospectively, not in hindsight.<sup>35</sup> It is difficult to prospectively identify the preterminal phase analytically, however, and currently available methods may produce a biased subpopulation.<sup>36</sup> Physicians tend to overestimate survival and consequently may not realize that the end of life is approaching for their patients, although their predictions are highly correlated with actual survival.<sup>37</sup> Several clinical scales exist, all with limitations, that provide marginal improvements over clinician estimates of survival,<sup>38</sup> but there are no clear “stopping rules” for anticancer treatment.<sup>39</sup> Refinement of these prognostic tools is an important area for future research.

Finally, further work is needed to establish the contribution of patient preferences to the aggressiveness of end-of-life care, and to

estimate the effect of aggressive care on outcomes such as overall survival, patient and family satisfaction with care and perceptions of quality, and cost. We have argued that patterns of injudicious use of anticancer treatment near the end of life may be a marker for lack of difficult end-of-life discussions with patients, poor prognostic ability, or a paucity of available palliative resources. It may also be patient driven, though, because patients and their families generally have not experienced the entire course of cancer through death and consequently may desire inappropriately aggressive care. It may not be possible to both achieve patient satisfaction and avoid futile care, but it is the physicians' responsibility to counsel patients and their families and advise them when it is time to stop anticancer treatments and focus on the need for effective palliative care as patients approach the end of life.

#### AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

#### AUTHOR CONTRIBUTIONS

**Conception and design:** Craig C. Earle, Jane C. Weeks, John Z. Ayanian

**Financial support:** Craig C. Earle

**Administrative support:** Craig C. Earle

**Provision of study materials or patients:** Craig C. Earle

**Collection and assembly of data:** Craig C. Earle

**Data analysis and interpretation:** Craig C. Earle, Mary Beth Landrum, Jeffrey M. Souza, Bridget A. Neville, Jane C. Weeks, John Z. Ayanian

**Manuscript writing:** Craig C. Earle

**Final approval of manuscript:** Craig C. Earle, Mary Beth Landrum, Jeffrey M. Souza, Bridget A. Neville, Jane C. Weeks, John Z. Ayanian

#### REFERENCES

- Rowland J, Mariotto A, Aziz N, et al: Cancer survivorship: United States, 1971-2001. *MMWR* 53: 526-529, 2004
- National Cancer Policy Board: Ensuring Quality Cancer Care. Washington, DC, National Academy Press, 1999
- Earle CC, Park ER, Lai B, et al: Identifying potential indicators of the quality of end-of-life cancer care from administrative data. *J Clin Oncol* 21:1133-1138, 2003
- Earle CC, Neville BA, Landrum MB, et al: Evaluating claims-based indicators of the intensity of end-of-life cancer care. *Int J Qual Health Care* 17: 505-509, 2005
- Earle CC, Neville BA, Landrum ME, et al: Trends in the aggressiveness of cancer care near the end of life. *J Clin Oncol* 22:315-321, 2004
- Lamont EB, Christakis NA: Physician factors in the timing of cancer patient referral to hospice palliative care. *Cancer* 94:2733-2737, 2002
- Grunfeld E, Lethbridge L, Dewar R, et al: Towards using administrative databases to measure population-based indicators of quality of end-of-life care: Testing the methodology. *Palliat Med* 20:769-777, 2006
- Murillo JR Jr, Koeller J: Chemotherapy given near the end of life by community oncologists for advanced non-small cell lung cancer. *Oncologist* 11:1095-1099, 2006
- Emanuel EJ, Young-Xu Y, Levinsky NG, et al: Chemotherapy use among Medicare beneficiaries at the end of life. *Ann Intern Med* 138:639-643, 2003
- Voogt E, van der HA, Rietjens JA, et al: Attitudes of patients with incurable cancer toward medical treatment in the last phase of life. *J Clin Oncol* 23:2012-2019, 2005
- Barnato AE, Herndon MB, Anthony DL, et al: Are regional variations in end-of-life care intensity explained by patient preferences? A study of the US Medicare population. *Med Care* 45:386-393, 2007
- von Gunten CF: Discussing hospice care. *J Clin Oncol* 21:31s-36s, 2003
- Jacobson M, O'Malley AJ, Earle CC, et al: Does reimbursement influence chemotherapy treatment for cancer patients? *Health Aff (Millwood)* 25:437-443, 2006
- Mack JW, Cook EF, Wolfe J, et al: Understanding of prognosis among parents of children with cancer: Parental optimism and the parent-physician interaction. *J Clin Oncol* 25:1357-1362, 2007
- Lee SJ, Fairclough D, Antin JH, et al: Discrepancies between patient and physician estimates for the success of stem cell transplantation. *JAMA* 285:1034-1038, 2001
- Weissman DE, O'Donnell J, Brady A: A cry from the fringe. *J Clin Oncol* 11:1006, 1993
- Weeks JC, Cook EF, O'Day SJ, et al: Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA* 279: 1709-1714, 1998
- Matsuyama R, Reddy S, Smith TJ: Why do patients choose chemotherapy near the end of life? A review of the perspective of those facing death from cancer. *J Clin Oncol* 24:3490-3496, 2006
- Slevin ML, Stubbs L, Plant HJ, et al: Attitudes to chemotherapy: Comparing views of patients with cancer with those of doctors, nurses, and general public. *BMJ* 300:1458-1460, 1990
- Mack JW, Wolfe J, Cook EF, et al: Hope and prognostic disclosure. *J Clin Oncol* 25:5636-5642, 2007
- Virnig BA, Kind S, McBean M, et al: Geographic variation in hospice use prior to death. *J Am Geriatr Soc* 48:1117-1125, 2000
- McCarthy EP, Burns RB, Ngo-Metzger Q, et al: Hospice use among Medicare managed care and fee-for-service patients dying with cancer. *JAMA* 289:2238-2245, 2003
- Keating NL, Herrinton LJ, Zaslavsky AM, et al: Variations in hospice use among cancer patients. *J Natl Cancer Inst* 98:1053-1059, 2006
- Virnig BA, Ma H, Hartman LK, et al: Access to home-based hospice care for rural populations: Identification of areas lacking service. *J Palliat Med* 9:1292-1299, 2006
- Virnig BA, Fisher ES, McBean MA, et al: Hospice use in Medicare managed care and fee-for-service systems. *Am J Manag Care* 7:777-786, 2001

26. Daugherty CK: Examining ethical dilemmas as obstacles to hospice and palliative care for advanced cancer patients. *Cancer Invest* 22:123-131, 2004
27. Christakis NA, Escarce JJ: Survival of Medicare patients after enrollment in hospice programs. *N Engl J Med* 335:172-178, 1996
28. Neuss MN, Jacobson JO, Earle C, et al: Evaluating end of life care: The Quality Oncology Practice Initiative (QOPI) experience. *J Clin Oncol* 20:486s, 2006 (suppl; abstr 8573)
29. Wennberg JE, Fisher ES, Stukel TA, et al: Use of hospitals, physician visits, and hospice care during last six months of life among cohorts loyal to highly respected hospitals in the United States. *BMJ* 328:607, 2004
30. Makuc DM, Haglund B, Ingram DD, et al: Vital and Health Statistics: Health Service Areas for the United States—Series 2: Data Evaluation and Methods Research 112. DHHS Publication No. (PHS) 92-1386, 1991
31. Grunfeld E, Coyle D, Whelan T, et al: Family caregiver burden: Results of a longitudinal study of breast cancer patients. *CMAJ* 170:1795-1801, 2004
32. Kristjanson L: Validity and reliability testing of the FAMCARE scale: Measuring family satisfaction with advanced cancer care. *Soc Sci Med* 36:693-701, 1993
33. Ayanian JZ, Chrischilles EA, Fletcher RH, et al: Understanding cancer treatment and outcomes: The Cancer Care Outcomes Research and Surveillance Consortium. *J Clin Oncol* 22:2992-2996, 2004
34. Donabedian A: The quality of care: How can it be assessed? *JAMA* 260:1743-1748, 1988
35. Bach PB, Schrag D, Begg CB: Resurrecting treatment histories of dead patients: A study design that should be laid to rest. *JAMA* 292:2765-2770, 2004
36. Earle CC, Ayanian JZ: Looking back from death: The value of retrospective studies of end-of-life care. *J Clin Oncol* 24:838-840, 2006
37. Glare P, Virik K, Jones M, et al: A systematic review of physicians' survival predictions in terminally ill cancer patients. *BMJ* 327:195-198, 2003
38. Stone PC, Lund S: Predicting prognosis in patients with advanced cancer. *Ann Oncol* 18:971-976, 2007
39. Benner SE, Fetting JH, Brenner MH: A stopping rule for standard chemotherapy for metastatic breast cancer: Lessons from a survey of Maryland medical oncologists. *Cancer Invest* 12:451-455, 1994

---

## Appendix

The Appendix is included in the full-text version of this article, available online at [www.jco.org](http://www.jco.org). It is not included in the PDF version (via Adobe® Reader®).